Title:

A narrative review of family members' experience of organ donation request after brain death in the critical care setting

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Abstract

Family members of critically ill patients suffer from high levels of anxiety and depression in the ICU, and are at risk of developing post-ICU syndrome following ICU discharge. In the case of brain death, and potential organ donation, the family is at the center of the decision process: within a limited time frame, the family will be informed that the patient is brain dead and will be approached about potential organ donation. Family experience with organ donation has been the topic of several research papers allowing to gain knowledge about family members' experience of organ donation, emphasizing specific needs, adequate support and pointing out gaps in current delivery of family-centered care. In this review, experts clinicians and researchers present the various legal systems regarding family implication in organ donation decisions; describe factors that influence the decision-making process; highlight family perspectives of care and respect for potential donors in the ICU environment; describe the impact of organ donation discussions and decisions on post-ICU syndrome; and suggest communication skills and support to be developed in the future. A research agenda for the next decade is also encouraged. Overall, challenges remain and concern all persons involved in the process, ICU doctors and nurses, the organ procurement organization, family members and, in some cases, the patients themselves. Looking at the big picture will provide opportunities for further improvements.

Background

The experience of family members (FMs) of intensive care unit (ICU) patients has received much attention in the past 30 years. Studies have demonstrated considerable psychological burden as FMs attempt to cope with uncertainty and overwhelming crisis. Throughout this stressful experience, FMs often have difficulty understanding and processing information provided by the medical team [1] and may also suffer from high levels of anxiety and depression [2]. During the months that follow, FMs are at risk of developing symptoms of post-ICU syndrome, such as anxiety, depression and post-traumatic stress [3]. Bereaved FMs are at higher risk of developing these symptoms as well as complicated grief [4].

Potential organ donors are admitted to the ICU, either with the initial hope of reversing their condition or with explicit intention to progress towards organ donation and transplantation. In the case of neurological determination of death (NDD), also known as brain death, and potential organ donation, the family is at the center of the decision process: within a limited time frame, the family will be told that the patient is brain dead and will be approached regarding potential organ donation. However, brain death can also occur in older patients with complex comorbidities at the end of a long illness and hospitalization. Clinicians must be mindful that decisions made in the ICU, including end-of-life decisions and organ donation decisions can remain with FMs long after the loss of their loved-one.

Caring for FMs is considered one of the ICU healthcare professionals' (HCP) major tasks. However, discussing deceased organ donation can be challenging both for HCPs who initiate and manage the conversations [5], and for the FMs. Many studies have shown that for FMs, communication with ICU HCPs is one of the most highly valued aspects of care [6-8] that impacts on their experience during the patient's stay and after the patient's death [3,4,9,10]. In the context of potential organ donation, quality of communication is vital and influences organ donation decisions. Sometimes ICU teams fail to approach families of potential organ donors as this discussion seems too challenging and/or because they are afraid of adding distress and burden to bereaved family members [11]. Collaboration with the Organ Procurement Organization (OPO) is essential both for FMs and for ICU healthcare professionals (Figure 1).

In this review, we seek to describe family members' experience of organ donation request after brain death in the critical care setting.

Methods

Authors of this review are clinicians and researchers who have extensive clinical and/or research experience in the field described. After a preliminary search of the literature using Pubmed and CINAHL databases (1990-2018), the corresponding author qualitatively derived four domains of publication using keywords such as "organ donation" and "family experience" (and equivalent terms such as family decision-making, family stress, family outcomes): 1) legal aspect of organ donation; 2) factors that influence the decision; 3) family perspective of care in the organ donation context; 4) impact of organ donation on families' psychological well-being. We narrowed literature to English language studies. The four domains were further developed by content experts. Supplemental Table 1 presents 15 major articles used in this paper. After receiving and examining the paragraphs written by the experts, NKB and EA merged and homogenized them, proposed a synthesis of communication skills and support to be developed in the future, and a research agenda that was then discussed and adjusted by all co-authors.

Opt-in and opt-out systems: different family roles?

The legal authority to procure a deceased person's organs comes from valid consent for donation. This consent or authorization can be given by the donor him/herself while living or, if the donor hasn't expressed a written wish, by the family. Depending on the system, the family's theoretical role is different.

Different Systems

In many countries, consent for donation relies upon a legal framework or at least on national recommendations. Overall, there are 2 legal consent systems: an opt-in (OI) system and an opt-out (OO) system (Figure 2 and Table 1). In an OI system, also called "explicit consent", the consent is expressed by the potential donor when he/she is living, as a positive intention to organ donation. This information can be found on a donor registry, a donor card, an official document (driving license, etc.), advance directives, or from a designated person. In an OO system, also called "presumed consent", or "deemed consent", everybody is considered a potential donor unless they express their wish not to donate (negative intention), either on a national registry or by signing a document or, depending on the law, by explicitly expressing this refusal to their family. Application of these rules in both systems varies between countries/regions, mainly concerning the approach of the family, leading to a "hard" (strict application of the system) or "soft" (approach adapted to family's experience) OI/OO system in place.

Theoretical family roles

In theory, each system should be rigorously applied and FMs should be aware of the law. In addition, the patient should systematically express his/her wish to donate (OI), or not to donate (OO), and the family should accept this expressed wish. Both systems share the same objective: to respect the patient's decision. The difference between them is the "default" treatment of someone who has not expressed a wish [12].

In theory, in an OI system, the FMs know the patient's wish. When approached regarding an organ donation decision, their role is to inform of the patient's wish regarding organ donation and to make sure it is respected. In an OO system, the FMs role is to confirm that the patient had never expressed a refusal for donation. Concurrently and whatever the system, their role is to protect their loved-one's body and expressed wishes. In all systems, the role of the OPO and HCPs is to ensure that the FMs understand the situation and the process, and that the

patient's wish will be respected. However, in some countries the OPO's role has raised controversy regarding its engagement in favor of organ donation and potential bias during communication with FMs.

The family's role in practice

In practice the theoretical and simple scenarios presented above are rare. Informing all citizens of the law (OD system) remains a challenge for public health services. In fact, in most countries, the system (OI or OO) is not rigorously applied because HCPs also have the family's well-being at heart. Caring for the bereaved family during this process is a responsibility as FMs are going through a unique and distressing experience. Moreover, the family has to accept and live with the decision once the process is over.

At the center of the process is knowledge of the patient's wish. If the latter isn't known, each system will consider the family's role differently but, *in fine*, the decision will be made by the family. Difficulties can also emerge when there is discordance between the patient's and the family's wishes. Although explicit individual consent is "binding", HCPs can take a contrary position by respecting the bereaved family's wishes [13], potentially creating a legal and/or ethical tension. The power of veto is not legally recognized in most countries although in practice, it is used everywhere [14].

The situation is complex for the family decision-makers (FDMs) who discuss organ donation with the OPO and HCPs as they must also face other relatives and friends: communicate and explain the situation as well as the next steps of the process. During these discussions, it can be difficult to identify who is the most legitimate relative to give "the consent". In the UK, Germany and Canada, the law has defined an official family hierarchy, however family members' acting in the official decision-making role may draw from other family members opinions as they convey the patient's wishes. This is particularly important in case of internal disagreement about donation. Within a given system, the family's role can also be influenced by social, cultural or religious considerations.

Overall, although both systems strive to place the patient's wishes at the center of the process, family members play a key role and can decide for the patient or even, in some cases, overrule the patient's wishes. Understanding reasons to refuse donation and family's experience during and after the process may help to both minimize family distress and fulfill the patient's wishes, whether their decision would be to donate or not to donate.

Reasons to refuse or accept organ donation: key factors influencing the decision

Family decision-makers (FDMs) become the gatekeepers to scarce, life-saving organs, particularly when patients have not formally made their wishes known. FDMs must make decisions, often during moments of trauma and acute grief that can have life or death consequences for many people on transplant waiting lists. Thus, the decision-making processes and understanding the reasons to authorize or refuse donation by FDMs has been an important subject of inquiry among organ donation researchers for the past three decades. The literature to date suggests that a variety of factors influence FDMs' authorization decisions.

The strongest and most consistent predictor of donation authorization is knowledge or awareness of the donor-eligible patient's wishes. FDMs' awareness of their loved ones' donation wishes is strongly associated with honoring those wishes [15-24]. A recent study found that 97.6% of FDMs who were aware of their family member's wish to donate did so as compared to 85.6% who did not [23]. Other studies have found similar patterns [15,16,20,24]. However, families are often not knowledgeable about the patient's wishes. One study of more than 1,000 FDMs reported that less than two-thirds were aware of their loved one's registration decision [23]. In the US, computerized State donor registries serve as a repository of patient's wishes, although only slightly more than half the adult US population is on the registry [25].

FDMs have consistently expressed a need for additional knowledge and accurate information about organ donation to aid in their decision-making [26]. In a recent survey of 118 family members of patients in the ICU, only 32% could answer four questions about organ donation correctly [27]. A majority of FDMs reported that receiving more information about donation while their loved one was in the ICU would have helped donation decision-making [27]. This is consistent with other studies that have shown higher authorization rates among FDMs who received more donation-relevant information [15,28,29]. Topics of particular importance to FDMs include: brain death (specifically, understanding brain death), the condition of the body after donation, costs incurred by the donor's family, and funeral arrangements [16,22,24,30].

The timing of information delivery is less important to FDMs than previously thought. The initial assumption that strictly separating the donation conversation from the brain death conversation or declaration of death – a concept known as decoupling – would increase authorization rates has been shown to be short-sighted. The available data suggest that having the donation conversation before the declaration of death is associated with authorization to

donation [19,31] and that separating discussions about EOL care and donation can decrease consent rates [32]. FDMs are also less likely to authorize donation if they feel "surprised" by the request [15,33].

Providing complete and accurate information in a timely fashion is important, but equally critical is the manner in which the information is delivered to the FDMs. HCPs are encouraged to employ multimodal communication, to ensure a proper setting for family meetings, and the presence of a support person [34]. The data indicate that the communication skills of OPO requesters can influence authorization decisions among FDMs [17,19,21,28,35-37], although this can also be overrated as shown in a recent study [32]. Effective communication is a skill that can be taught and learned. Notably, a communication skills training intervention for OPO requesters increased time spent with FDMs discussing donation, number of donation-related topics discussion, and increased authorization rates from 46.3% pre-intervention to 55.5% post-intervention [28]. Further, FDMs noted improved communication, including higher levels of sincerity, honesty, cooperation, and listening, among requesters who completed the communication skills training intervention [35]. FDMs were also less likely to feel pressured by the OPO requesters who participated in the training intervention [35]; the literature indicates that FDMs who feel harassed or pressured are less likely to authorize donation [15].

Finally, of critical importance is increasing our understanding of the donation decision-making needs and preferences of racial/ethnic minority groups [14]. In the United States, African Americans have significantly lower authorization rates than the general population [14]. However, studies have shown that requesters spend less time with African American families discussing donation and provide less information to them compared to Caucasians [38]. Moreover, African American FDMs are less likely to register as organ donors [39] and also less likely to know the donation wishes of their loved ones [38]. Finally, there are many racial/ethnic groups about whom we know little. The current literature suggests that tailoring donation-related educational interventions to the unique needs of racial/ethnic minority groups may increase authorization rates and help remediate these persistent disparities [40,41].

Family perspectives of care and respect for potential organ donors

An integral part of end-of-life care in the ICU is identifying and responding to the needs of FMs who encounter an organ donation decision. A family-centred approach to intensive care recognizes that family members are often at the centre of decisions concerning their critically ill or injured relative, and this can place a significant burden [42]. Exploratory research with bereaved families into the reality of donation decision-making has informed understanding of family-centred issues and specific support needs. Among family-reported experiences of deceased donation is the commonly mentioned need for their relative to be treated with care and respect [43-52].

Respecting a relative's autonomous choice to donate their organs after death, and the consolation of knowing that lives may be saved are powerful decision-making motives behind family consent. Evidence suggests that donor families are intent on turning a tragic situation into something positive [49-52] and this can manifest in determination to fulfil a relative's expressed wish to be an organ donor [50, 52]. Health professionals play a key role in helping families to accomplish the hopes and expectations of donation [53] and this can be optimised by the involvement of specialist staff [54, 55]. Researchers have emphasised the importance of organ donor advocacy behaviour in the ICU, both to safeguard the will and wishes of the potential donor and his/her family and to protect the dignity of the deceased [56]. Researchers in the UK found that honouring the wishes of the potential donor was important to grieving families, yet this was not foremost in their thoughts at a time of acute psychological distress. Retrospectively, families positively acknowledged healthcare staff that brought the possibility of organ donation to their attention [52, 53]. As with consent decisions, some families suggest that declining donation is respecting a relative's wish not to donate their organs [47, 50].

The concepts of care and respect also materialize in family narratives about the effects of organ donation on their relative. A need to protect the deceased person's body can lead to decisional conflict; overtly evidenced in one study as a tension between the 'gift of life' and 'sacrifice of the body' for organ donation to proceed [48]. A more recent study describing the donation-decision making dilemmas of families depicted a similar struggle with utilitarian considerations and protecting the deceased's body [43]. In some cultures, preserving body integrity has a religious or spiritual meaning that families protectively respect [46, 49, 50]. Equally, perceived violation of the body, prolonged suffering, and possible futility of removing organs unsuitable for transplantation can lead to non-donation [48]. Appropriate

physiological support before and after brain death is necessary for successful donation [57]. However, for the grieving family, perceptions of keeping their relative 'alive' for the purpose of donation after brain death can be a source of emotional turmoil in the context of end-of-life care [58]. Thus, understanding families' imagery and providing factual explanation of what the process of organ donation involves are important steps in helping to allay notable fears and concerns [59, 60]. Families also need reassurance that their relative will be cared for with reverence both during and after organ retrieval [46, 51, 52].

Family satisfaction with the provision of care for their relative is a significant correlate of the decision to donate [44, 45, 52]. In the former study, FMs' expressed need for their relative to be treated with dignity and respect was paramount regardless of the final donation decision [44]. An observed respectful deed was caring for and speaking to their relative as though he/she were conscious and alive [44, 52]. Likewise, skilled communication is essential to enabling family acceptance of death and consideration of organ donation [61]. It is well known that families experience internal conflict between the appearance of their relative and the impending or actual loss of life [30], particularly so in the case of brain death [62]. The family experience of brain death and organ donation has been explained in a theory of Dissonant Loss depicting a sequential process of conflict and resolution [63]. The findings of this seminal research have resonance with and meaning for donor family care policy today. However, an evidence-base for contemporary practice is incomplete. Further understanding of what drives family donation decision-making, including the significance of care and respect is essential to the provision of quality end-of-life care, and in supporting families to reach an optimal and enduring decision [60].

Impact of organ donation on post-ICU family outcomes

The impact of organ donation processes on FMs' psychological well-being during the months that follow the patient's death has received little attention.

A first group of studies showed the negative impacts of some aspects of the organ donation process on bereaved FMs. Interestingly these negative impacts were due to factors that could be improved in the ICU setting. A study assessing grief symptoms [64] in a large number of relatives of brain-dead patients for whom organ donation was discussed in the ICU showed that one month after the patient's death, relatives of non-donors describe a significantly more burdensome experience: they were more dissatisfied with communication, more often shocked by the request and more often found the decision difficult. Interestingly, decisional regret more often occurs when the decision was to decline donation [65] and when organ donation was raised before FMs were informed of the patient's death [66].

Quality of communication is important: understanding the cause of death is necessary for families to give meaning to the patient's death. Research shows that not understanding brain death is associated with an increased risk of developing complicated grief [64]. A small randomized controlled trial showed that family presence during brain death evaluation improved understanding of brain death with no apparent adverse impact on psychological well-being [67]. Lack of understanding may hinder the grieving process. In the months and even years that follow the patient's death, FMs describe the questions they felt they should have asked at the time, but were too distressed to do so [68]. A qualitative study [69] has shown that relatives' ambivalent decision-making style and perception of health care professionals' behaviour as "organ focused" appear to be risk factors for traumatic memories. In another qualitative study [70], clinicians' quality of communication (quality information and ability to listen to the relatives) affected donation decision-making and appeared to impact on the relatives' grieving process. Moreover, dissatisfaction with hospital care was associated with depressive and grief symptoms [71,72].

Nonetheless, information and support do not stop at the patient's death. Families who want but lack information about the transplantation outcomes experience more stress throughout their grief as well as uncertainty about their decision to donate [73]. This suggests that a proactive follow-up by the OPO (telephone call, card or letter) may help promote family well-being [63,68]. The absence of adequate bereavement support means that families have to live

with unanswered questions [34,73]. Follow-up needs are of course variable and responses require flexibility: further research is needed to better understand FMs' needs in this field.

A second group of studies show that the decision itself (donation/refusal) neither hinders nor furthers the grief process [3,4,64,71,74]. As shown in Figure 3, if bereaved FMs are more at risk than non-bereaved FMs of developing Post-ICU Syndrome, implication in an organ donation process does not alter the risk of developing such symptoms. If families of non-donor patients experience the process as significantly more burdensome, it is interesting to note that the decision itself (donation vs refusal) isn't associated with grief symptoms over the 9 months that follow the patient's death [64]. As shown in another follow-up study of FMs, levels of depression and problems with detachment from the deceased are similar among bereaved families of donor and non-donor patients as well as families who were not approached for post-mortem organ donation [71]. In a qualitative study in the paediatric context, consent or refusal of organ donation *per se* did not seem to affect the overall grieving process. It is the meaning attributed to the act of donation that affects how parents perceive the child's death and subsequently facilitates or hinders their adjustment to loss [75].

Most qualitative studies have focused on families of donor patients and show that the act of donation may assist families in their grief [76,77] and have a beneficial effect on the bereavement process [72,77]. Those who felt most comforted reported fewer symptoms of depression [72]. For some families the decision to donate is beneficial in the bereavement process, for various and sometimes very different reasons such as the knowledge that donation had benefitted people, the belief that the deceased person "lives on", or the feeling that the death was not in vain [53]. Qualitative studies focusing on families of non-donor patients are lacking and should be developed in the future (Table 2).

These data show that more than the decision itself, it is the quality of the process that impacts on family outcomes in the months that follow the patient's death: quality information that permits to understand and accept the death as well as adapted support. This leaves room for strategies to improve communication in this specific setting.

Perspectives for the future

What family support can we provide?

In the ICU, brain death remains an end-of-life situation that requires similar communication and support strategies as other EOL situations, such as available HCPs to help FMs understand the situation and to show respect to the patient. As shown in Table 3, communication skills must be developed both by ICU doctors and nurses, and by the OPO specialists.

Organ donation cannot remain the OPO's preoccupation only. All ICU clinicians are concerned as research shows that the more the FMs have the opportunity to discuss the subject with HCPs, including those who actually care for the patient, the more likely they are to accept donation [15] and to feel comfortable with the process [64]. Cooperation between ICU HCPs and members of the OPO is paramount to optimize organ procurement [78] and supports the embedding of teamwork principles in the design and delivery of organ donation training programs. The ICU culture plays an important role [11] and one must favor an approach that includes all HCPs, ICU doctors and nurses as well as the OPO. Encouraging a positive attitude to FMs of potential organ donors cannot be separated from clinicians' experience of EOL in the ICU. A more holistic and collaborative approach (ICU team/OPO) [79] may help overcome certain barriers or apprehensions and improve attitudes and support offered to FMs.

What research should be developed? (Table 2)

Improving FMs' experience of organ donation process as well as long term family outcomes remains an important challenge. Qualitative research will permit better insight into cultural/ethic specific experiences, as deeper knowledge of cultural aspects of organ donation is needed. It will also help understand who initiates organ donation discussions and whether this has an impact on consent rates. This approach will also allow better insight into the positive effects of organ donation, such as involvement in community work, participation in support programs for other FMs or promoting organ donation education. Interventional studies should also be designed to examine the impact of specific support programs during decision-making (32), as well bereavement support programs, on family outcomes. Moreover, research should focus on FMs and clinicians simultaneously to best understand the dynamic that underpins decision-making. Other precise questions still remain unanswered such as the

impact of matching the requesters to FMs' culture on consent rates and family well-being. Research is also needed to enhance the understanding of family veto in organ donation.

Future research should approach the potential conflict between a documented living will and organ donation as tension can develop in situations where patients have expressed "anti-treatment" wishes as well as the wish to be an organ donor. Better insight into families' and clinicians' experience as well as practical answers to these situations are needed.

Another important research topic concerns the patients themselves, as in certain situations they may be conscious and competent to consent in the ICU, such as patients with end stage neuromuscular diseases on invasive or non-invasive ventilation, or, in certain countries, patients requiring medical assistance in dying (or euthanasia). In this context, patients', FMs' and HCPs' experiences should be studied as well as discussions and organization of EOL care and organ donation process.

Last, it is crucial to develop research projects in the field of organ donation after the circulatory determination of death (DCD) that accounts for a growing percentage of deceased organ donations. FMs' experience in this context can be complex as not only are they involved in the decisional process to withdraw life-sustaining therapies, but they are then involved in the organ donation decisional process. Better understanding their involvement in this specific situation is pressing, including their perception of the dying process and their experience of decision-making.

Limitations

First, we opted for a narrative review as we believe it is the most suitable review method for this topic in that it provides for a comprehensive appraisal of the state of current knowledge, and critically considers a wide range of issues that will feed debates to come. Second, much of the data is observational and stems from the US, Canada or Australia, and raises the question of generalizability to the European or other international contexts. However, research is being developed in Europe and results are not incoherent with those of previous published studies. Last, many references include only small sample size and the strength of evidence is very weak. However these studies provide interesting data that will help design future larger studies.

Conclusion

Research has permitted to gain considerable knowledge concerning FMs' experience of organ donation in the case of brain death and has enabled HCPs to better understand their needs and expectations. However, challenges remain and concern all persons involved in the process, ICU doctors and nurses, the OPO, FMs and, in some cases, the patients themselves. Looking at the big picture, rather than only at some elements will provide opportunities for further improvements. Moreover, time has come to expand research to FMs and organ donation after circulatory determination of death – a field under explored to date.

Figure legends:

Figure 1: People involved in organ donation discussions in the ICU

ICU = Intensive Care Unit

OD = Organ Donation

Figure 2: Opt-in and Opt-out systems and existence of donor and non-donor registries in Europe

Panel A: Consent Systems in Europe

Opt-in system

Opt-out system

Mixed system = Combination of opt-in and opt-out systems

Panel B: Donor and non-donor registries in Europe

Donor= Donor registry

Non-Donor = Non-Donor registry

Both = Both Donor and Non-Donor registries

None = No registry at all

Figure 3: Post-ICU syndrome in 3 groups of ICU family members

This figure displays post-ICU syndrome-family (PICS-F) in three groups of patients, namely, overall ICU relatives (blue line), relatives of patients who died in the ICU (red line), and relatives of organ donor patients (green line). Relatives of overall ICU patients present less symptoms of depression or PTSD than other groups of relatives. Bereaved relatives report similar rates of post-ICU syndrome, regardless if death was associated organ donation or not.

1. Azoulay E, Chevret S, Leleu G et al (2000) Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med 28(8):3044-9

2. Pochard F, Azoulay E, Chevret S et al (2001)Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit Care Med 29(10):1893-7

3. Azoulay E, Pochard F, Kentish-Barnes N et al (2005) Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med 171(9):987-94

4. Kentish-Barnes N, Chaize M, Seegers V et al (2015) Complicated grief after death of a relative in the intensive care unit. Eur Respir J 45(5):1341-52

5. Potter JE, Herkes RG, Perry L et al (2017) COMmunication with Families regarding ORgan and Tissue donation after death in intensive care (COMFORT): protocol for an intervention study. BMC Health Serv Res 17(1):42

6. Nelson JE, Mulkerin CM, Adams LL et al (2006) Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. Qual Saf Health Care 15:264–271

7. Nelson JE, Puntillo KA, Pronovost PJ et al (2010) In their own words: patients and families define high-quality palliative care in the intensive care unit. Crit Care Med 38(3):808-18.

8. Long AC, Curtis JR (2014) Quality of dying in the ICU: understanding ways to make it better. Intensive Care Med 40(11):1793

9. Davidson JE, Jones C, Bienvenu OJ (2012) Family response to critical illness: post intensive care syndrome-family. Crit Care Med 40(2):618-24

10. Gries CJ, Engelberg R, Kross EK et al (2010) Predictors of symptoms of post-traumatic stress and depression in family members after patient death in the ICU. Chest 137 (2): 280-287

11. Kentish-Barnes N, Duranteau J, Montlahuc C et al (2017) Clinicians' Perception and Experience of Organ Donation From Brain-Dead Patients. Crit Care Med 45(9):1489-1499

12. den Hartogh G (2012) The role of the relatives in opt-in systems of postmortal organ procurement. Medicine, Health Care and Philosophy 15(2):195–205

13. Rosenblum AM, Horvat LD, Siminoff LA et al (2012) The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. Nephrol Dial Transplant 27(6): 2533–2546

14. Toews M, Caulfield T (2016) Evaluating the "family veto" of consent for organ donation. CMAJ. 188(17-18):E436-E437

15. Siminoff LA, Gordon N, Hewlett J, Arnold R (2001) Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation. JAMA 286(1):71-77

16. Siminoff LA, Mercer MB, Graham G, Burant C (2007) The Reasons Families Donate Organs for Transplantation: Implications for Policy and Practice. J Trauma Inj Infect Crit Care 62:969–978

17. Walker W, Broderick A, Sque M (2013) Factors influencing bereaved families' decisions about organ donation: an integrative literature review. West J Nurs Res 35:1339–59

18. Rodrigue JR, Cornell DL, Krouse J, Howard RJ (2010) Family initiated discussions about organ donation at the time of death. Clin Transplant 24:493–9

19. Simpkin AL, Robertson LC, Barber VS, Young JD (2009) Modifiable factors influencing relatives' decision to offer organ donation: systematic review. 338:b991

20. López JS, Martínez JM, Soria-Oliver M et al (2018) Bereaved relatives' decision about deceased organ donation: An integrated psycho-social study conducted in Spain. Soc Sci Med 205:37–47

21. Miller C, Breakwell R (2018) What factors influence a family's decision to agree to organ donation? A critical literature review. London J Prim Care (Abingdon) 10:103–107

22. Frutos MA, Blanca MJ, Mansilla JJ et al (2005) Organ donation: a comparison of donating and nondonating families. Transplant Proc 37:1557–9

23. Traino HM, Siminoff LA (2013) Attitudes and acceptance of First Person Authorization: A national comparison of donor and nondonor families. J Trauma Acute Care Surg 74(1): 294–300

24. Siminoff LA, Arnold RM, Hewlett J (2001) The process of organ donation and its effect on consent. Clin Transplant 15:39–47

25. U.S. Department of Health and Human Services (2018) Organ Donation Statistics. In: U.S. Gov. Inf. Organ Donation Transplant. https://www.organdonor.gov/statistics-stories/statistics.html. Accessed 15 Oct 2018

26. Sarti AJ, Sutherland S, Healey A et al (2018) A Multicenter Qualitative Investigation of the Experiences and Perspectives of Substitute Decision Makers Who Underwent Organ Donation Decisions. Prog Transplant 28(4):343-348

27. Michetti CP, Newcomb A, Thota V, Liu C (2018) Organ donation education in the ICU setting: a qualitative and quantitative analysis of family preferences. J Crit Care 48:135–139

28. Siminoff LA, Marshall HM, Dumenci L et al (2009) Communicating effectively about donation: an educational intervention to increase consent to donation. Prog Transpl 19:35–43

29. Siminoff LA, Molisani AJ, Traino HM (2015) A comparison of the request process and outcomes in adult and pediatric organ donation. Pediatrics 136:e108–e114

30. Ralph A, Chapman JR, Gillis J et al (2014) Family perspectives on deceased organ donation: thematic synthesis of qualitative studies. Am J Transplant 14:923–35

31. Siminoff LA, Lawrence RH, Zhang A (2002) Decoupling: What is it and does it really help increase consent to organ donation? Prog Transplant 12:52–60

32. Potter JE, Perry L, Elliott RM et al (2018) Communication with Families Regarding Organ and Tissue Donation after Death in Intensive Care (COMFORT): a multicentre before-and-after study. Crit Care Resusc 20(4):268-276

33. de Groot J, van Hoek M, Hoedemaekers C et al (2016) Request for organ donation without donor registration: a qualitative study of the perspectives of bereaved relatives. BMC Med Ethics 17:38

34. Sarti AJ, Sutherland S, Healey A et al (2018) A Multicenter Qualitative Investigation of the Experiences and Perspectives of Substitute Decision Makers Who Underwent Organ Donation Decisions. Prog Transplant 28(4):343-348

35. Siminoff LA, Traino HM, Genderson MW (2015) Communicating Effectively about Organ Donation: A Randomized Trial of a Behavioral Communication Intervention to Improve Discussions about Donation. Transplant direct 1:1–9

36. Haddow G (2004) Donor and nondonor families' accounts of communication and relations with healthcare professionals. Prog Transplant 14:41–48

37. Rodrigue JR, Cornell DL, Howard RJ (2008) Pediatric organ donation: What factors most influence parents' donation decisions? Pediatr Crit Care Med 9:180–185

38. Siminoff LA, Lawrence RH, Arnold RM (2003) Comparison of black and white families' experiences and perceptions regarding organ donation requests. Crit Care Med 31:146–51

39. Siminoff LA, Burant CJ, Ibrahim SA (2006) Racial disparities in preferences and perceptions regarding organ donation. J Gen Intern Med 21:995–1000. https://doi.org/10.1007/BF02743151

40. Flemming SSC, Redmond N, Williamson DH et al (2018) Understanding the pros and cons of organ donation decision-making: Decisional balance and expressing donation intentions among African Americans. J Health Psychol https://doi.org/10.1177/1359105318766212

41. Russell E, Robinson DH, Thompson NJ, Perryman JP, Arriola KRJ (2012) Distrust in the healthcare system and organ donation intentions among African Americans. Journal community health, 37(1):40-47

42. Davidson JE, Aslakson RA, Long AC et al (2017) Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med 45:103-128

43. de Groot J, van Hoek M, Hoedemaekers C et al (2015) Decision making on organ donation: the dilemmas of relatives of potential brain dead donors. BMC Med Ethics 16:64 Doi 10.1186/s12910-015-0057-1 https://bmcmedethics.biomedcentral.com/track/pdf/10.1186/s12910-015-0057-1 Accessed 02 February 2019

44. Jacoby LH, Breitkopf CR, Pease EA (2005) A qualitative examination of the needs of families faced with the option of organ donation. Dimens Crit Care Nurs 24:183-189

45. DeJong W, Franz HG, Wolfe SM et al (1998) Requesting organ donation: an interview study of donor and non-donor families. Am J Crit Care 7:13-23

46. Shih FJ, Lai MK, Lin MH et al (2001) The dilemma of '*to-be or not-to-be*': Needs and expectations of the Taiwanese cadaveric organ donor families during the pre-donation transition. Soc Sci Med 53: 693-706

47. Moraes ELD, Massarollo MCKB (2008) Family refusal to donate organs and tissue for transplantation. Rev. Latino-Am. Enfermagem 16:458-464

48. Sque M, Long T, Payne S et al (2008) Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'? J Adv Nurs 61:134-144

49. Bellali T, Papadatou D (2007) The decision-making process of parents regarding organ donation of their brain dead child: A Greek study. Soc Sci Med 64:439-450

50. Neate SL, Marck CH, Skinner M et al (2015) Understanding Australian families' organ donation decisions. Anaesth Intensive Care 43:42-50

51. Bastami S, Krones T, Biller-Andorno N (2016) Relatives' experiences of loved ones' donation after circulatory and brain death. A qualitative inquiry. Bioethica Forum 9:17-25

52. Sque M, Walker W, Long-Sutehall T et al (2018) Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making. J Crit Care 45:82-89

53. Walker W, Sque M (2016) Balancing hope and despair at the end of life: The contribution of organ and tissue donation. J Crit Care 32:73-78

54. Jansen NE, van Leiden HA, Haase-Kromwijk BJ et al (2011) Appointing 'trained donation practitioners' results in higher family consent rate in the Netherlands: a multicenter study. Transplant Int 24: 1189-1197

55. Hulme W, Allen J, Manara AR et al (2016) Factors influencing the family consent rate for organ donation in the UK. Anaesth 71:1053-1063

56. Forsberg A, Lennerling A, Fridh I et al (2015) Attitudes towards organ donor advocacy among Swedish intensive care nurses. Nurs Crit Care 20:126-133

57. McKeown DW, Bonser RS, Kellum JA (2012) Management of the heartbeating brain-dead organ donor. Br J Anaesth 108(S1): i96-i107

58. Sque M, Morgan M, Randhawa G et al (2013) Bereaved families' experiences of organ and tissue donation, and perceived influences on their decision making. Final Report submitted to the British Department of Health.

59. Sque M, Galasinski D (2013) 'Keeping her whole': bereaved families' accounts of declining a request for organ donation. Camb Q Healthc Ethics 22:55-63

60. Shemie SD, Robertson A, Beitel J et al (2017) End-of-life conversations with families of potential donors: Leading practices in offering the opportunity for organ donation. Transplantation 101: S17-S26

61. Mills L, Koulouglioti C (2016) How can nurses support relatives of a dying patient with organ donation option? Nurs Crit Care 21:214-224

62. Erwin J, Kompanje O (2015) Families and Brain Death. Semin Neurol 35:169-173

63. Sque M, Payne SA (1996) Dissonant loss: The experiences of donor relatives. Soc Sci Med 43:1359-1370

64. Kentish-Barnes N, Chevret S, Cheisson G et al (2018) Grief symptoms in relatives who experienced organ request in the ICU. Am J Respir Crit Care Med 198(6):751-758

65. Jacoby L, Jaccard J (2010) Perceived support among families deciding about organ donation for their loved ones: donor vs nondonor next of kin. Am J Crit Care 19(5):e52–61

66. Rodrigue JR, Cornell DL, Howard RJ (2008) The instability of organ donation decisions by next-of-kin and factors that predict it. Am J Transplant 8(12):2661–7

67. Tawil I, Brown LH, Comfort D et al (2014) Family presence during brain death evaluation: a randomized controlled trial. Crit Care Med 42(4):934-42

68. Sque M, Long T (2003) Organ and tissue donation: exploring the needs of the families. Summary of the final report sponsored by the British Organ Donor Society

69. Kesselring A, Kainz M, Kiss A (2007) Traumatic memories of relatives regarding brain death, request for organ donation and interactions with professionals in the ICU. Am J Transplant 7(1):211-217

70. Sque M, Long T, Payne S (2005) Organ donation: key factors influencing families' decision-making. Transplant Proc 37:543-546

71. Cleiren MP, Van Zoelen AA (2002) Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. Death Stud 26(10):837-849

72. Merchant DJ, Yoshida EM, Lee TK et al (2008) Exploring the psychological effects of deceased organ donation on the families of the organ donors. Clin Transplant 22:341-347

73. Ralph A, Chapman JR, Gillis J et al (2014) Family perspectives on deceased organ donation: thematic synthesis of qualitative studies. American Journal of Transplantation 14:923-935

74. Stocks L, Cutler JA, Kress T, Lewino D (1992) Dispelling myths regarding organ donation: the donor family experience. J Transplant Coord 2:147-152

75. Bellali T, Papadatou D (2006) Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? Death Studies 30(10):883-917

76. Stouder DB, Schmid A, Ross SS at al (2009) Family, friends, and faith: how organ donor families heal, Progress in Transplantation 19(4):358-61

77. Kentish-Barnes N, Cohen-Solal Z, Souppart V et al. Being convinced and taking responsibility: a qualitative study of family members' experience of organ donation decision and bereavement after brain death. Crit Care Med 2019 [Epub ahead of print]

78. Wojda TR, Stanislaw PA. Stawicki SP et al (2017) Keys to successful organ procurement: An experience-based review of clinical practices at a high-performing health-care organization. Int J Crit Illn Inj Sci 7: 91-100

79. Domínguez-Gil B, Coll E, Elizalde J et al (2017) Expanding the Donor Pool Through Intensive Care to Facilitate Organ Donation: Results of a Spanish Multicenter Study. Transplantation 101(8):e265-e272

Table 1: Opt-in and Opt-out systems in different countries concerning organ donation from deceased persons

Country	National consent system	Donor registry	Non-donor registry
Austria	Opt-out	No	**Yes**
Belgium	Opt-out	No	**Yes**
Bosnia Herzegovina	Opt-out	No	No
Bulgaria	Opt-out	No	**Yes**
Croatia	Opt-out	No	**Yes**
Cyprus	Opt-in	**Yes**	No
Czech Republic	Opt-out	No	**Yes**
Denmark	Opt-in	**Yes**	**Yes**
Estonia	Opt-out	**Yes**	**Yes**
Finland	Opt-out	NA	NA
France	Opt-out	No	**Yes**
Germany	Opt-in	No	No
Greece	Opt-out	No	**Yes**
Hungary	Opt-out	No	**Yes**
Iceland	Opt-in	NA	NA
Ireland	Opt-in	NA	NA
Italy	Opt-out	**Yes**	**Yes**
Latvia	Opt-out	**Yes**	**Yes**
Lithuania	Opt-in	**Yes**	No
Luxembourg	Opt-out	NA	NA
Malta	Opt-out	**Yes**	No
Montenegro	Opt-in	No	**Yes**
Netherlands	Opt-in	**Yes**	**Yes**
Norway	Opt-out	NA	NA
Poland	Opt-out	No	**Yes**
Portugal	Opt-out	No	**Yes**
Romania	Opt-in	**Yes**	No
Russia	Opt-out	No	No
San Marino	Opt-out	NA	NA
Serbia	Opt-in	**Yes**	No
Slovakia	Opt-out	No	Yes
Slovenia	Mixed system	**Yes**	**Yes**
Spain	Opt-out	**Yes**	**Yes**
Sweden	Mixed system	**Yes**	**Yes**
Switzerland	Opt-in	**Yes**	**Yes**
Former Yugoslav Republic of Macedonia	Opt-in	NA	NA
Turkey	Opt-in	**Yes**	No
United Kingdom	Mixed system (opt-put in Wales)	**Yes**	**Yes**
Some countries outside Europe			
Australia	Opt-in	**Yes**	**Yes**
New-Zealand	Opt-in	No	No
Canada	Opt-in	**Yes**	No
Japan	Opt-in	No	No
USA	Opt-in	**Yes**	No

NA: data not available. Note: some countries do not have registries, but advanced will directives fulfil this requirement. Table adapted from: Legal provisions in European countries for consent to/authorisation of organ donation from deceased persons, P85 in Guide to the quality and safety of organs for transplantation : https://www.edqm.eu/en/organs-tissues-and-cells-technical-guides. [accessed 10th November 2018]"

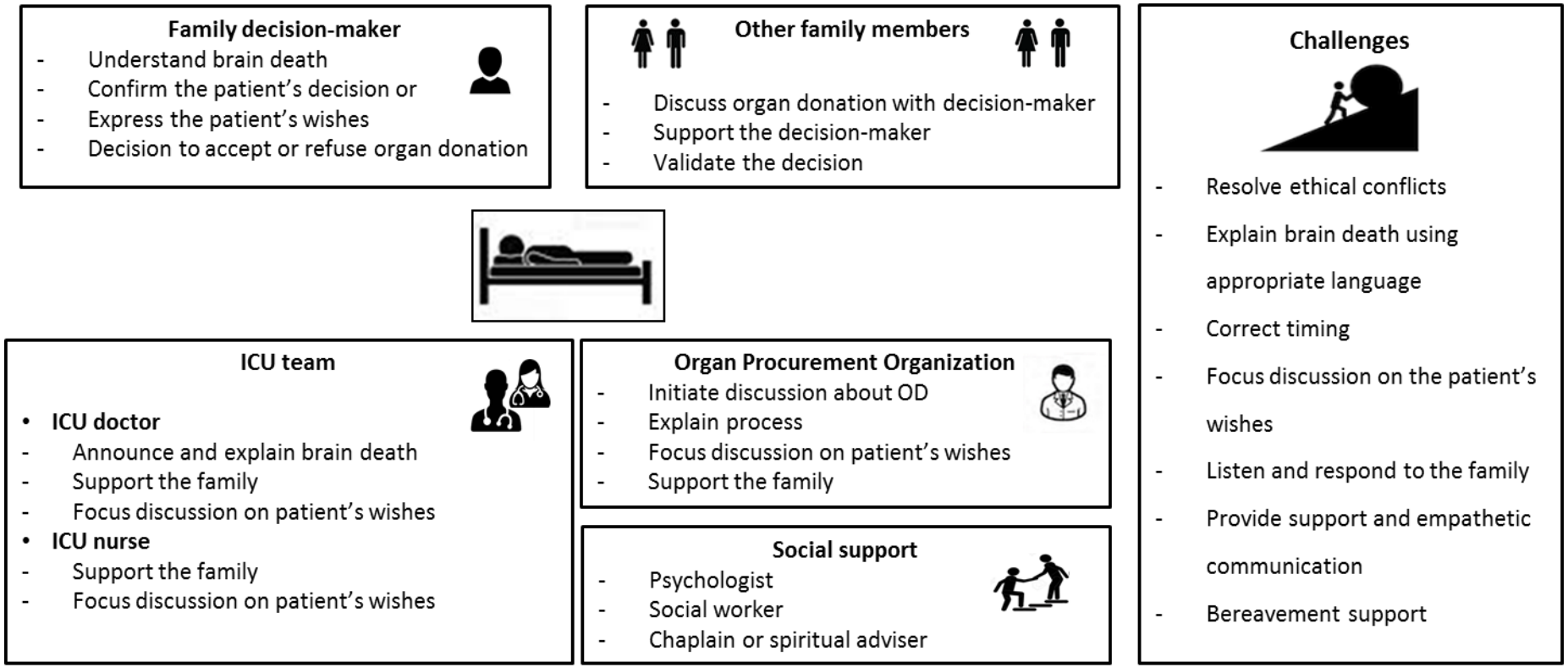
Table 2: Research agenda

Family orientated research	Clinician orientated research
Understand the donation decision-making needs and preferences of racial/ethnic minority groups	Examine impact of clinicians' specialized training on family outcomes [5]
Understand the minutiae of the dynamic interaction at the time of the approach and discussion about organ donation: a prospective ethnographic observation study [52]	Examine impact of clinicians' specialized training and awareness on clinicians' experience and on clinician's perception of family experience
Causal research to test for an association between a positive family care experience and consent to donation [52]	Examine the effectiveness of 'teamwork training' on team behavior, performance, and organ donation outcomes in ICU
Understand refusal and decisional regret: in depth qualitative research Enhance understanding of family veto	Examine the effectiveness of training using simulation on clinicians' experience and on family outcomes
Understand family outcomes in other donation settings (donation after the circulatory determination of death)	Examine the effectiveness of interventions to improve clinicians' skills to communication about brain death
Explore the impact of system level variables on family member outcomes, including impact of opt in and opt out legislation	Unit staff level: examine the impact of communicating about transplantation outcomes for brain dead donor patients who were hospitalized in the ICU on clinicians' motivation and satisfaction
Test specific support programs during decision-making period Test tailored bereavement support programs	Examine the effectiveness of a standardized organ donation procedure on family outcomes

Table 3: Suggestions to improve communication skills

Upstream	
	Better inform citizens about their organ donation system (Opt-in / Opt-out) and donor or non-donor registries
	Physician and nurse education about organ donation and brain death in order to improve knowledge and communication skills
In the ICU	
Clinician orientated	Develop organ donation culture in the ICU: explicit communication about organ donation with physicians and nurses
	Unit staff level: communicate about transplantation outcomes for brain dead donor patients who were hospitalized in the ICU
Family orientated	Provide optimal communication, similar to other end-of-life situations (family conference, VALUE mnemonic: Value the family, Acknowledge emotions, Listen, Understand family emotions, Elicit family questions)
	Timing: - Timing the conversation about organ donation: prepare the conversation about organ donation. However, brain death and organ donation conversations do not have to be separate - Adequate time spent with family members (do not rush)
	Explain brain death in a clear and understandable manner - Give meaning to the patient's death
	Focus on the patient: - The patient's wishes (and decision) - The patient's dignity - The respect of the patient's body - Help families honor the wishes of the potential donor
	Adequate support during emotional turmoil: - Understand families' imagery associated to organ donation - Provide factual explanations - Provide reassurance
	Communication adapted to cultural context and ethnic origin
	Listen to and answer family members' questions - Be attentive to verbal and non-verbal communication - Show empathy
After the ICU	
	Adapted support at the morgue (when the family discovers the patient's "cold body")
	Available clinicians to answer questions about the process
	Adapted bereavement support and screening for prolonged grief and other symptoms of post-ICU burden

Figure 1: People involved in organ donation discussions in the ICU



ICU: Intensive Care Medicine; OD: Organ Donation

Figure 2

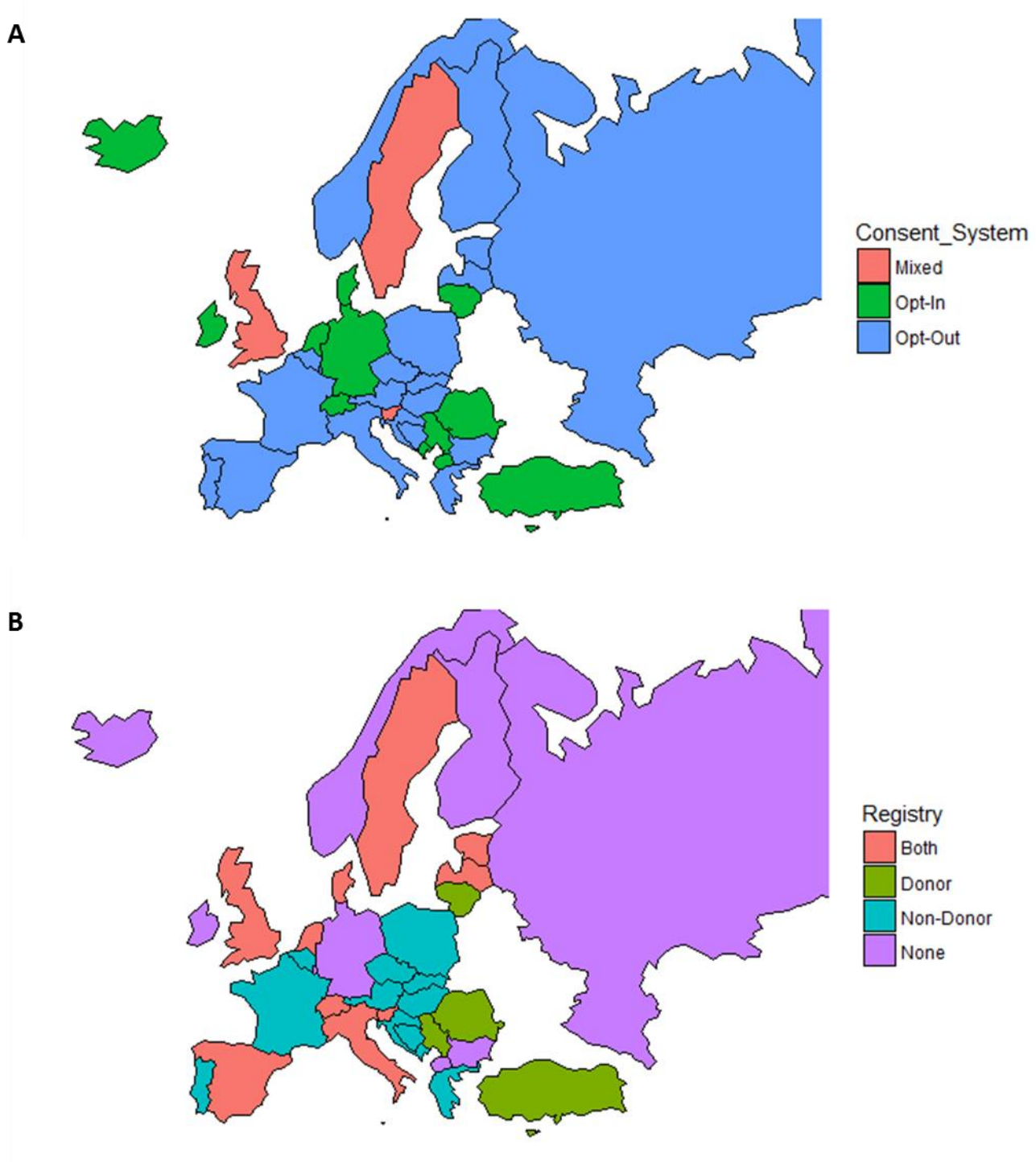
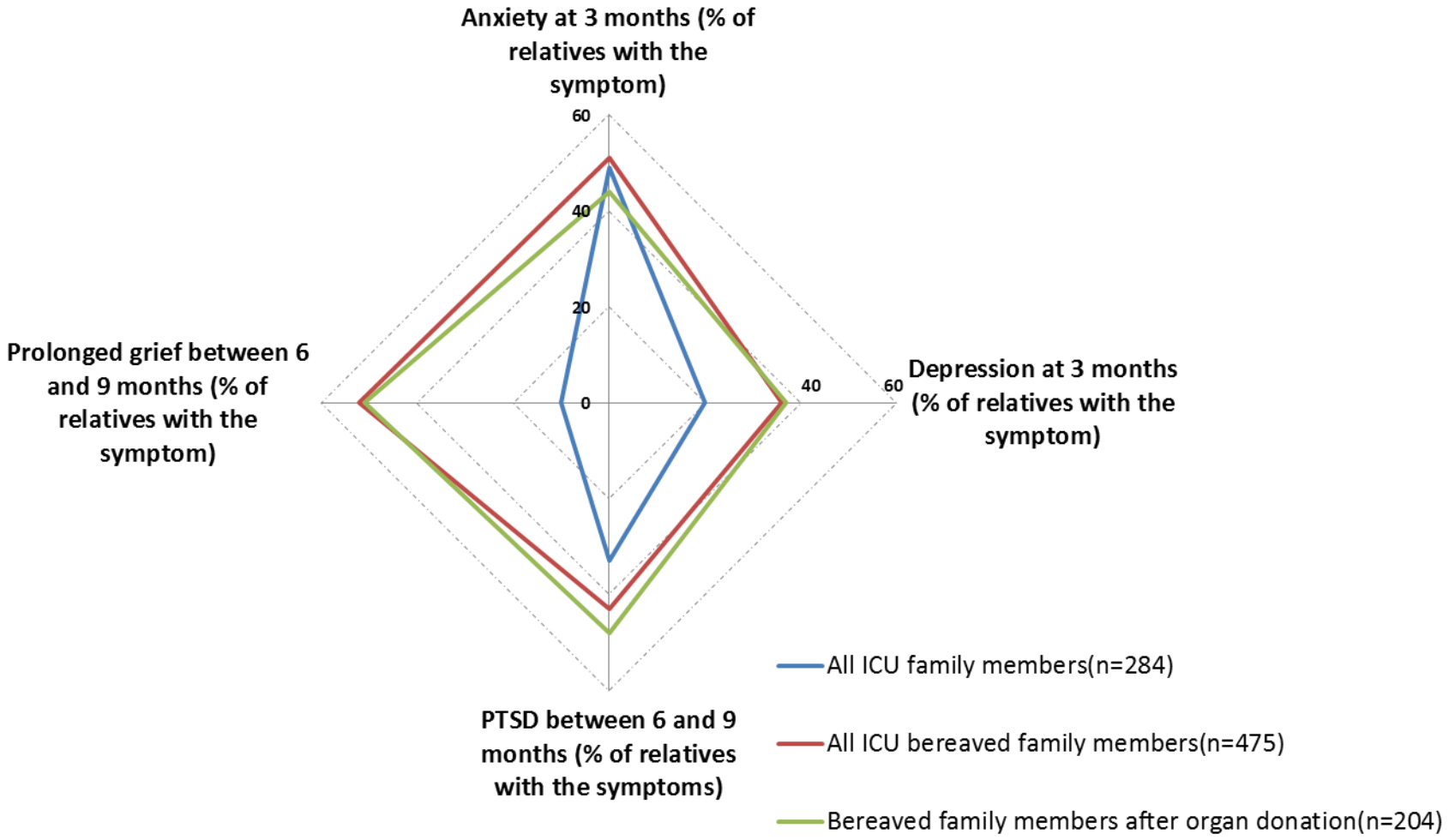

A
Consent_System
Mixed
Opt-In
Opt-Out
B
Registry
Both
Donor
Non-Donor
None

Figure 3: Post-ICU syndrome in 3 groups of ICU family members



Azoulay et al, AJRCCM 2005; Kentish-Barnes et al, ERJ 2015; Kentish-Barnes et al, AJRCCM 2018